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## EXPLORING THE CHALLENGES OF ACCESSING MEDICATION FOR PATIENTS WITH CYSTIC FIBROSIS

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3 **EXPLORING THE CHALLENGES OF ACCESSING MEDICATION FOR**  
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5 **PATIENTS WITH CYSTIC FIBROSIS**  
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47 SH, NR, SS, AS were involved in concept, design, data collection, analysis and preparing the  
48  
49 final manuscript. PW and ZE involved in the data collection, analysis and preparing the final  
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53 preparing the final manuscript.  
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58 **Keywords:** Cystic fibrosis, medication, treatment burden  
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19 deemed this work not to require ethical approval on 30/4/2019.  
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24 **Abbreviations:** CF: Cystic Fibrosis; CFTR: Cystic Fibrosis Transmembrane Conductance  
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26 Regulator; GP: General Practitioner (Primary Care Doctor); JLA: James Lind Alliance;  
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28 MDT: Multi-disciplinary Team; PSP: Priority Setting Partnership; PwCF: people with CF.  
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### 32 33 **Abstract (99 words)**

34  
35 Reducing treatment burden in cystic fibrosis (CF) is the top research priority for patients and  
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37 clinicians. Difficulty accessing medication is one aspect of treatment burden. We investigated  
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39 this with an online survey available globally for CF patients and health care professionals.  
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42 Almost three quarters of CF patients in our survey report difficulty getting repeat  
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44 prescriptions on time and most community pharmacists experience interrupted supplies of CF  
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46 specific medications. These barriers affect emotional and physical health of people with CF.  
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49 Two thirds of people with CF would like to get all their CF medication from one place, their  
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51 CF centre.  
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### 54 55 56 57 58 **Introduction** 59 60

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3 Reducing treatment burden for patients with CF was voted the number one research priority  
4 by people with CF (pwCF), their parents/carers and healthcare professionals in a James Lind  
5 Alliance Priority Setting Partnership. (1) 'Treatment burden' describes the increased  
6 workload associated with health care affecting individuals' physical and psychological  
7 wellbeing (2). The James Lind CF2 project further explored this research priority.  
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17 CF is a multisystem disease requiring complex treatment including specialist medications  
18 (e.g. inhaled antibiotics and CFTR modulators) and non-specialist drugs (e.g. bronchodilators  
19 and multivitamins), the latter being drugs which are used almost exclusively in the treatment  
20 of pwCF which are usually prescribed by the CF team. High treatment burden is common to  
21 many chronic diseases, resulting in reduced adherence, wasted medication, health  
22 deterioration and poorer quality of life. (3)(4) Treatment burden for pwCF is considerable –  
23 most spend around two hours per day on treatment. (5) Accessing prescribed medications is  
24 an issue for patients with chronic diseases which contributes to treatment burden. (6) We  
25 aimed to review the obstacles pwCF encounter when accessing medications and to  
26 demonstrate insight from professionals who provide medications (pharmacists and primary  
27 care doctors).  
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## 45 **Methods**

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47 The James Lind CF2 project explores in depth some of the research priorities identified by  
48 the James Lind Alliance priority setting partnership for CF. (1) It is supported by the UK  
49 National Institute for Health Research (NIHR) and the UK CF Trust. An online survey for  
50 pwCF was conducted generating free-text data on accessing medications (5). A further survey  
51 for primary care doctors and community pharmacists (with guidance from a focus group) was  
52 distributed using SurveyMonkey™ and was available for 4 weeks in June 2019. Both  
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3 quantitative ‘single answer’ and qualitative ‘free text’ questions were incorporated. A final  
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5 questionnaire to pwCF (July 2019) asked; ‘should all medication be accessed from secondary  
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7 care?’.  
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12 The questionnaires were not country-restricted and were promoted via social media. They  
13  
14 were anonymous; no personal data were stored, or financial incentive given. All responses to  
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16 the questionnaires were non-compulsory. Data were downloaded into Excel for quantitative  
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18 analysis and into NVivo for qualitative analysis. Prior to commencing this work we published  
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20 our protocol at:  
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24 <https://nottingham-repository.worktribe.com/output/2226944>  
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### 33 **Results**

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35 James Lind CF2 question “Do you ever have difficulties getting the medications you need  
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37 from your GP/Pharmacist/hospital/homecare?” found 76% (241/317) of pwCF had difficulty  
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39 accessing medication (5). The demographics of the participants have previously been  
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41 published (5). Of the pwCF who had difficulty accessing medication, 65 participants  
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43 expanded with a free text response following on from the quantitative question. Six recurring  
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45 themes were identified. (Figure 1) Emotive language was used in free-text responses  
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47 describing challenges that pwCF experienced in accessing their medication (Figure 2).  
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54 The healthcare professionals’ survey yielded 256 responses, including 249 from the UK.  
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56 Almost a third of respondents did not have pwCF in their cohort (31%; 78/249), with the  
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58 majority having one or two pwCF 45% (114/249). Primary care doctors accounted for 16% of  
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3 the responses (40/249). Data on prescribing revealed that 39% (13/33) lacked confidence  
4 when prescribing CF specialist medication and 50% (17/34) had been asked to prescribe  
5 medication that should be prescribed by secondary care. Suggestions on how the CF centre  
6 can support primary care included education, ensuring up-to-date guidelines and having  
7 access to discuss care. Many pwCF did not see value from primary care doctors' input, and  
8 some primary care doctors felt that their role was 'limited as there is such good access to  
9 specialists'. However, others perceived their role to be caring for the pwCF outside of the CF  
10 condition, *'including mental health, contraception, and vaccinations'*.

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24 Community pharmacists describe their role as a medication dispenser to ensure continuous  
25 treatment and optimising adherence. Difficulties obtaining medication supplies are reported  
26 by 55% (52/94) of community pharmacists including: pancreatic enzyme replacement  
27 therapy; dornase alfa; CF specific vitamin preparations; and colistimethate sodium. *'Supply*  
28 *problems are a major issue, this is not a pharmacy problem but industrial pharmaceutical*  
29 *companies causing the delay'*. Some specialist medications have a quota restricting supply,  
30 *'for example a manufacturer restricts supply to 2 per month, but you have a script for 12'*.  
31 Expensive medications with short shelf-lives are not kept in stock because of the potential for  
32 waste if treatment is changed. For routine repeat-prescriptions, 48% (95/196) of pharmacies  
33 require 1-2 days' notice. For specialist medication 39% (75/196) of pharmacies require 3-4  
34 days' notice with 10% (19/196) requiring 1-2 weeks' notice. Only 40% (76/192) of these  
35 have online repeat prescriptions requests.

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54 PwCF and health care professionals were asked if all medication should be prescribed and  
55 accessed in secondary care (Figure 3). Overall, 65% (25/40) pwCF wanted to access  
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3 medication from secondary care. Reservations included travel distance, car parking and  
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5 hospital pharmacy delays.  
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## 10 **Discussion**

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12 We present a complex process undertaken by pwCF to access medication, including 76% of  
13 those surveyed expressing difficulty getting repeat prescriptions from primary care. Our data  
14 suggest that this is part of the high treatment burden impacting upon physical and mental  
15 health.  
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24 Although each group interviewed has specific difficulties and frustrations, all are agreed on  
25 the need to simplify the process. Research shows that patients with chronic diseases have  
26 difficulty accessing medication, issues including pharmacy stock, medication errors and short  
27 durations of prescriptions (7) – all issues raised in our study. This is exacerbated by the  
28 number of medications pwCF take (average 8 daily) (8).  
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38 Primary care doctors and community pharmacists describe the barriers to accessing  
39 medication including practitioners' lack of familiarity with specialist medication and  
40 interrupted supplies. A guide to improving the logistics of obtaining medicines in the  
41 community offers pwCF and their families, practical suggestions on how to reduce such  
42 difficulties (9). Primary care doctors suggested that better communication with the CF centre  
43 and accessible guidelines would support their prescribing. The UK National Health Service  
44 (NHS) long-term plan (2019) aims for electronic prescribing (10) which may improve  
45 communication between the CF centre and primary care.  
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3 Our study has limitations. Respondents were self-selected and those with negative  
4 experiences might be more motivated to participate. We did not survey CF centres. Not every  
5 respondent answered every question. The CF patient cohort responding to ‘Should all  
6 medication be accessed from secondary care?’ was a smaller group than the James Lind CF2  
7 initial survey. We did not enquire as to whether a delivery service would aid access to  
8 medications. The surveys were conducted prior to the COVID-19 pandemic which might  
9 have altered responses, if patients were apprehensive about the infection risk in attending  
10 hospital. The strengths include the global reach and large number of responses to our original  
11 survey (941 responses from 21 countries) (1).  
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## 26 **Conclusion**

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28 Accessing medication is a problem for pwCF adding to the high treatment burden, impacting  
29 upon both the emotional and physical health. The next step is for targeted quality  
30 improvement plans to help reduce treatment burden.  
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#### Conflicts of interest:

AS reports a research grant and personal fees from Vertex. He has spoken at meetings supported by Teva and Novartis. These activities are outside the submitted work. In addition, Prof. Smyth has a patent *alkyl quinolones as biomarkers of pseudomonas aeruginosa infection and uses thereof issued*.

AD reports personal fees from Gilead, Chiesi, Novartis, ALK Abello and has attended dinners supported by Gilead and Chiesi, all outside the submitted work.

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Confidential: For Review Only

Theme	Quotations
<b>Short duration of medication dispensed 26% (17/65)</b>	'They will only give 28 days supply of some of the items on prescription even when it's medicine that my daughter will be on for the rest of her life'
<b>Perceived futility of primary care medication reviews 8% (5/65)</b>	'An 8-weekly review [of medications] at hospital doesn't count', 'My medications are usually reviewed by the practice nurse [primary care] who has no experience of CF'
<b>Delay in accessing acute medication 14% (9/65)</b>	'It can be frustrating if we urgently need something that the local pharmacist doesn't routinely stock. Ciprofloxacin has been the classic case - as soon as a swab result is phoned in as requiring this specialised antibiotic, they don't have it in stock which means a trip to the hospital'
<b>Difficulty in accessing a continuous supply of repeat prescription medication 49% (32/65)</b>	'Often suppliers run out of medication and I have waited over 1 month for a nebuliser supply and went without it for that time.', 'Even after ordering a week in advance they [local pharmacy] don't always have everything we need', 'Usually I have an extra 2 weeks of stock to avoid complications when meds are unavailable.'
<b>Primary care prescribing errors 26% (17/65)</b>	'I am constantly chasing the GP [primary care doctor] because medications are not prescribed within the stated 48 hours, only partially prescribed, prescribed in the wrong form (for example liquid instead of capsules) or in the wrong dosage (especially Creon).'
<b>Poor communication between primary, secondary care and the service user 34% (22/65)</b>	'When the GP and hospital can't agree who will supply what, [it is] annoying', 'Sometimes the GP doesn't update the prescription after the instructions from the hospital. It takes time to chase up and sort out'

Figure 1. Quotations from pwCF and their families for each theme identified. GP= General Practitioner (Primary care doctor)

189x178mm (157 x 157 DPI)

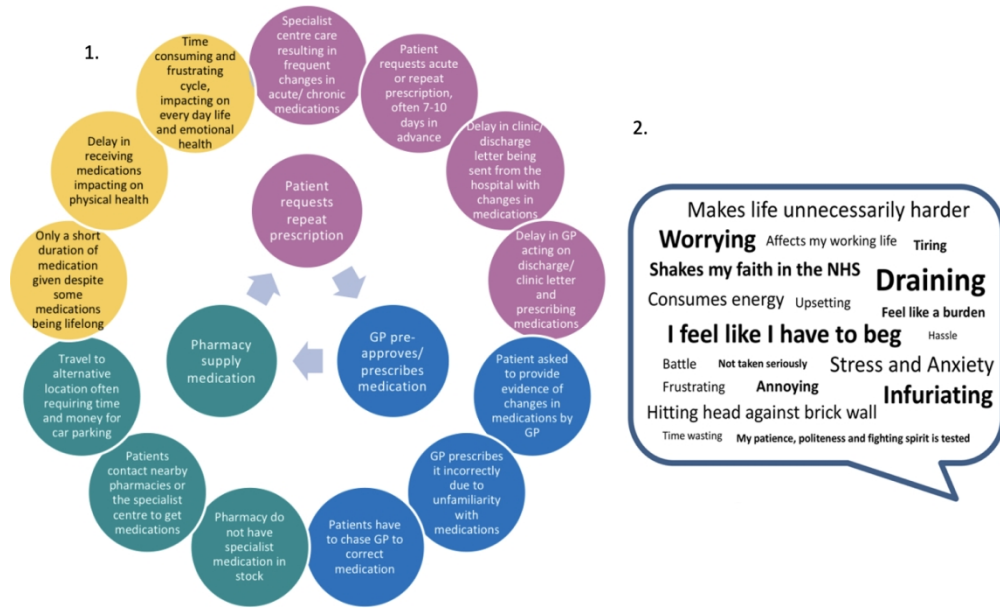


Figure 2. 1. Inner flow chart depicts the journey to accessing medications where the patient does not have a chronic, multisystem disease. The outer circle is a pathway described by the CF patient group that they take to access medications 2. Emotive language used by the patient group to describe the cycle in 1.

97x62mm (400 x 400 DPI)

### Should all CF medications be accessed via secondary care?

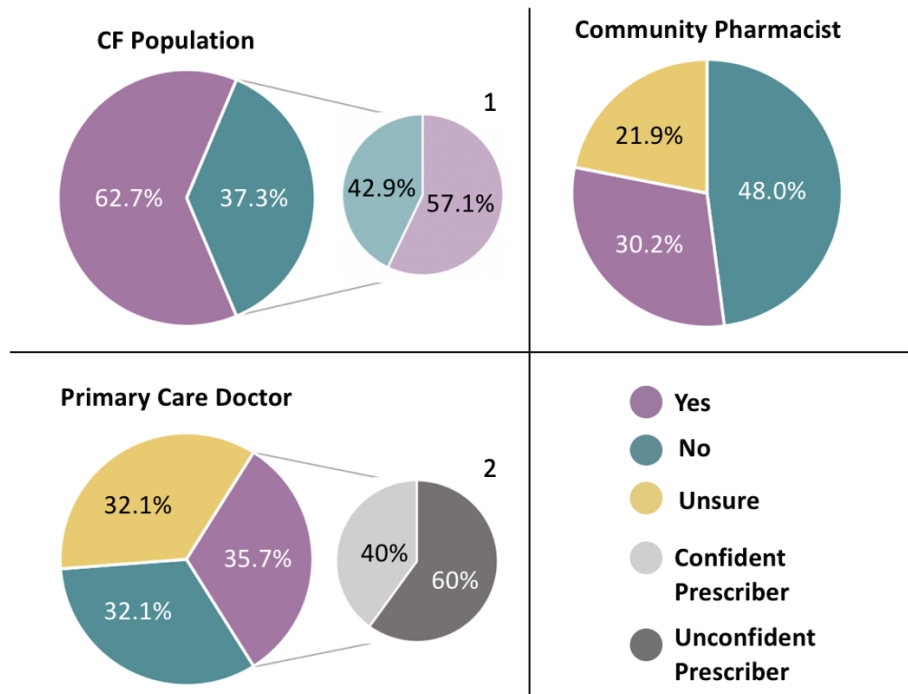


Figure 3. Should all medications be accessed from secondary care? Responses from the CF population, Community pharmacists and primary care. 1. For those that answered 'No' if travel was not an issue, would they change their mind? 2. For primary care doctors who said 'No', how many were confident at prescribing

73x59mm (400 x 400 DPI)